

NETWORK NEWS

News from the Utah Birth Defect Network

August 2006

<http://health.utah.gov/birthdefect>

Volume 3, Issue 2

The Utah Birth Defect Network:

Who Are We?

The Utah Birth Defect Network (UBDN) is a public health birth defect surveillance program that monitors the occurrence of all major structural malformations in the state. The UBDN is a program within the Bureau of Children with Special Health Care Needs, Division of Community and Family Health Services, at the Utah Department of Health. The UBDN seeks to prevent birth defects and secondary disabilities by monitoring occurrence, conducting epidemiological studies, providing education and outreach.

What do we do?

In addition to tracking the occurrence of birth defects, the UBDN staff works to educate both women and their health care providers throughout the state. The UBDN would like women to know before getting pregnant, what they can do that will improve their chances of having a healthy baby. Not only is it important to prevent birth defects from occurring, but it is as important when a child is born with a birth defect to minimize the physical, social and developmental problems that may occur as a result of the primary birth defect.

Why do we do it?

In Utah at least 1,400 babies are born with birth defects each year. Because birth defects impact every possible organ system most people do not realize how common these are in Utah. 1 in 33 babies are born with a major birth defect. Birth defects are the leading cause of infant deaths and contribute to babies being born prematurely. Monitoring prevalence rates allows us to identify trends and evaluate potential risk factors. Ultimately, epidemiological studies will lead to prevention strategies. Having a child with a birth defect is a life changing event. It is also the beginning of a lifelong journey with challenges and rewards. In this journey, some families may feel alone or feel they need information and support. The UBDN recognizes this need and would like to provide a support network for parents and children dealing with birth defects in the state of Utah. This support network will be created to facilitate family to family connections among those dealing with similar conditions.

We need your help!

None of this is possible without your help. Family to Family connections can only be made as we reach out to one another. If you would like to meet other parents in your area, please contact the UBDN and make the first connection. We want to hear from you! We want to know more about your individual situation and the challenges you face. We also want to know what you would like to see in a support network for families. We need your input and ideas to make the UBDN family to family tree grow. The UBDN support network includes all families that are dealing with birth defects in the state of Utah.

Inside this issue:

Family to Family Connection	2
Adding life to years: exploring quality of life in children with birth defects	3
From the Outreach Desk	3

Utah Birth Defect Network

P.O. Box 144699

Salt Lake City, Utah

84114-4699

Phone Number: 801-257-0566

Fax Number: 801-257-0572

Toll-Free: 866-818-7096



Family to Family Connections: Getting to Know YOU!

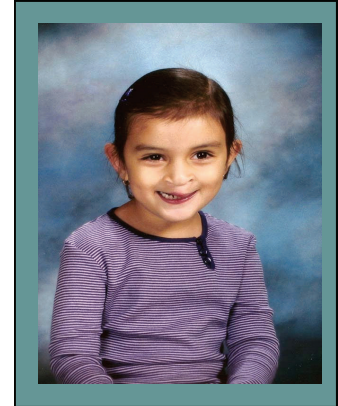


The Utah Birth Defect Network is proud to profile the Poulson Family from Springville, UT.

Hi! My name is Jade Poulson. I was born on December 18, 2001 and surprised my mom and dad with a severe bilateral cleft lip and palate. My mom had three ultrasounds, and each time they checked for cleft lip and palate (CLP), I just kept my hands held tight in front of my face. (I hid myself because I didn't want my mom to worry about me while she was pregnant.) I am currently 4-years-old and have had several surgeries including: premaxilla repositioning, palatal prosthesis, sepa-

rate lip closures, soft palate reconstruction, ear tubes, and most recently, hard palate reconstruction. A total of about 10 in all! I enjoy going to see my doctor at PCMC. His name is Dr. Louis Morales. Not only does Dr. Morales think I'm cute, but he's very happy with how I've come along with the surgeries. He's told me several times that I was one of the most severe cases he's ever seen, meaning my palatal openings were very wide! I have been involved in early intervention since I was about 18-months old! I attended Kids Who Count in Salem and am currently attending Sage Creek Elementary's Early Intervention Preschool in Springville for speech therapy and physical therapy. In addition to my CLP I also have acute Oculomotor Apraxia which mildly affects how my eyes and brain communicate! I love all of the Disney Princesses and teaching my little brother how to sing my favorite songs!

I am far from being done with surgeries, but as I've gotten older, things have just become easier on me and my parents and we definitely feel as though we've been very blessed! If you want to talk to my parents, you can email them at: vlinder23@msn.com.



Cleft lip and/or palate occurs when the tissues of the mouth or lip don't form properly during fetal development. A cleft lip is a long opening between the upper lip and the nose. A cleft palate is an opening between the roof of the mouth and the nasal cavity.

At the Utah Birth Defect Network (UBDN) we seek to prevent birth defects and secondary disabilities monitoring occurrence, conduct studies and provide education and outreach. We support a network for parents and children dealing with birth defects in Utah. We want your feedback and comments. Please contact us with your questions and ideas, kfowles@utah.gov.



Birth Defects: A Lifelong Journey

We are (in the process of) planning our second annual Family Meeting January 2007.

Watch for details on our website

<http://health.utah.gov/birthdefect/>

Adding life to years: exploring quality of life in children with birth defects

At the Utah Birth Defect Network we recognize that quality of life is important. We are a team of clinicians, nurses, epidemiologists, and economists, and have developed pilot studies to look at quality of life among people with birth defects.

These studies are difficult. Quality of life includes multiple dimensions of health. It has to incorporate personal perceptions and values. And it has to be assessed in ways that account for how perceptions change with the growing child.

In our pilot study we are asking some important questions. How do families and individuals evaluate their quality of life? What aspects are most affected by having a birth defect? What can families tell us that can make the future generations of quality of life studies better and more relevant to their needs and their issues?

In this pilot we focus on craniofacial anomalies, including facial clefts such as cleft lip and cleft palate. They are common birth defects, and even more so in Utah, which has one of the highest rates in the world for facial clefts (1 in every 450 babies). They can lead to considerable illness and disability, because problems

with feeding, hearing, and speech. Surgeries can be numerous and complex. The treatment can be costly. And they affect the face, putting affected people at risk for social, personal, and psychological concerns.

Currently, we are in the midst of collecting information about quality of life among children who were born with cleft lip and/or cleft palate. We have already contacted many of the parents either by phone or mail to participate in our studies of quality of life. To date we have interviewed 25 parents of affected children and 2 parents of unaffected children as a comparison. We would like to interview 55 more parents of affected children and 38 more parents of unaffected children.

We have also received by mail questionnaires from 12 parents of affected children and 7 from parents of unaffected children. We have just begun to receive the mail questions and would like to have 280 completed before we are finished. If you receive the questionnaire packet in the mail we invite you to complete it and return it to us. Your participation will greatly help us in completing this part of our study.

We have conducted two focus groups, one in Salt Lake County and one in eastern Idaho. Both fo-

cus groups were well attended and we obtained useful and previously unknown information. We are particularly appreciative of those parents who have spent their time with us in these focus groups. We are currently in the process of analyzing the tape recordings of the focus groups.

These studies are exciting and groundbreaking. They would not be practically or financially possible without the Utah Birth Defect Network. It is because of UBDN's structure, data, and cooperation with medical and public health professionals and families, that we can begin evaluating and addressing these important issues for all families in Utah. We thank those who have completed interviews and questionnaires and look forward to further interactions with you, the parents, and children with cleft lip and/or cleft palate.

Lorenzo Botto, M.D.

Medical Epidemiologist, University of Utah
Utah Birth Defect Network

From the Outreach desk:

As the Parent Outreach Coordinator at the Utah Birth Defect Network, I am constantly meeting new people. Recently, Sylvie L and Rosemary D called me. Sylvie and Rosemary are two seventh graders who are making a difference in the community. They have begun a campaign to educate other children about cleft lip and palate. They are also working to raise money for Operation Smile. (Operation Smile volunteers repair childhood facial deformities while building public and private partnerships that advocate for sustainable health-care systems for children and families.) Sylvie and Rosemary are selling candy and home-made starburst wrapper wallets to local children in their school. All proceeds will be given to Operation Smile. Hats off to Sylvie and Rosemary for making the extra effort to educate others in the prevention and education of birth defects! There

are many opportunities for you to become involved.

- **Education Outreach:** teach others about birth defects including causes and prevention.
- **Financial Contributions:** donating funds to support research into causes and prevention.
- **Research Participation:** willingness to participate in ongoing research studies concerning birth defects in the state of Utah.
- **Parent Support Network:** providing social and emotional support to parents and children dealing with birth defects

Having a child with a birth defect changes the way you view the world. The challenges that accompany the journey are often arduous and overwhelming.

Families are dealing with difficult issues, struggling with newly diagnosed birth defects and the new set of expectations that come with caring for a child with special needs. Most of the families I meet enthusiastically express a desire to meet other families dealing with similar challenges. This is where parents often find the support they need to accept their lot and move forward. It is with great excitement that the UBDN announces family to family connection. This will be a forum for families to connect with one another. Help us help you by finding other families dealing with similar issues. Please tell us about your situation. Contact Kristin at kfowles@utah.gov or call the UBDN at (801) 257-0566 to be added into our family network.

Kristin Fowles, Outreach Coordinator

Would you like to help the Utah Birth Defect Network grow?

We are working on prevention activities and educating the public about birth defects in Utah.

Please call us at (866) 818-7096 or (801) 257-0566

Utah Birth Defect Network
PO Box 144697-4697
Salt Lake City, Utah 84114-4697

STAMP

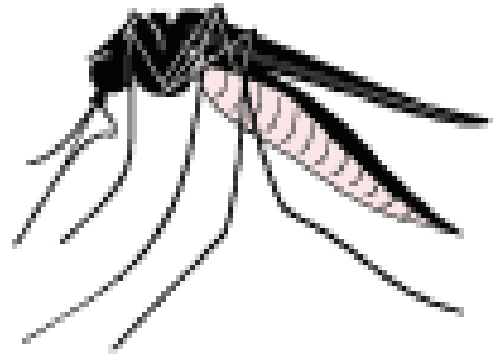


Place Label Here

Check out our new web-site!

www. health.utah.gov/birthdefect

Important Information About West Nile Virus



- West Nile Virus is likely to hit this summer.
 - More than 41,000 women will be pregnant during the peak season (July-September).
 - The risk to a pregnant woman are not well defined, but may be of concern.
 - More information can be found in a previous versions of this newsletter at http://health.utah.gov/birthdefect/downloads/Network_News_2-1.pdf
-